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Feeding difficulties in patients with advanced dementia – an analysis of convictions of Norwegian and Polish care staff

Trudności w żywieniu pacjentów w zaawansowanym stadium demencji – analiza przekonań norweskiego i polskiego personelu opiekuńczego

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A – Study Design, **B** – Data Collection, **C** – Statistical Analysis, **D** – Data Interpretation, **E** – Manuscript Preparation, **F** – Literature Search, **G** – Funds Collection

Summary **Background.** Feeding difficulties in severely demented patients present a significant challenge for all involved in care. Recent studies have found that there are differences between nurse's attitudes toward artificial nutrition and hydration in different countries.
Objectives. The aim of the study was to offer an analysis of convictions of Norwegian and Polish caring staff toward feeding problems in patients with advanced dementia and explore the way they cope with such situations.
Material and methods. The data was collected in the "Engensenteret" nursing home in Bergen (Norway) and in Medical Centre nursing home in Brzeg (Poland). The study group comprised 52 participants and involved staff taking care of severely demented patients. A self-constructed questionnaire was used.
Results. Contrary to the Norwegians, all Polish respondents favored forced feeding of severely demented patients. Almost half of respondents suggested that any decisions about aggressive feeding should be made separately by physician and none would offer decision-making power to the patient's family. Polish respondents stated significantly more often that artificial nutrition will improve quality of life in demented patients.
Conclusions. 1. The convictions of Norwegian and Polish respondents according introduction of artificial nutrition in end-stage dementia and its efficiency in this population were significantly different. 2. The respondents of both nations would generally delegate the decision-making power separately to the physician. 3. The development of nutritional guidelines for advanced dementia and correction of common misconceptions about the effectiveness of aggressive nutritional intervention in this population is recommended.
Key words: advanced directives, ethical dilemmas, feeding difficulties, forced feeding.

Streszczenie **Wstęp.** Trudności w odżywianiu pacjentów w zaawansowanej demencji stanowią ogromne wyzwanie dla personelu sprawującego nad nimi opiekę. Liczne badania potwierdziły, że postawy pielęgniarek wobec problemu sztucznego odżywienia i nawadniania pacjentów są różne w poszczególnych państwach.
Cel pracy. Analiza przekonań norweskiego i polskiego personelu opiekuńczego, dotyczących problemów w odżywianiu występujących u pacjentów z zaawansowaną demencją i wyjaśnienie, jak respondenci sobie z nimi radzili.
Materiał i metody. Badanie przeprowadzono w domu opieki "Engensenteret" w Bergen (Norwegia) oraz w Zakładzie Opiekuńczo-Leczniczym Brzeskiego Centrum Medycznego w Brzegu (Polska). Grupa badana składała się z 52 członków personelu opiekuńczego. Jako narzędzia badawczego użyto kwestionariusza własnej konstrukcji.
Wyniki. Wszyscy polscy respondenci, w przeciwieństwie do grupy norweskiej, opowiadali się za przymusowym karmieniem pacjentów z zaawansowaną demencją. Prawie połowa respondentów twierdziła, iż każdą decyzję dotyczącą sztucznego odżywiania i nawadniania powinien podjąć lekarz, nikt z badanych nie oddałby prawa decyzji w tej sprawie rodzinie chorego. Polscy respondenci twierdzili istotnie częściej, że sztuczne odżywianie poprawia ogólną jakość życia chorego na demencję.
Wnioski. 1. Przekonania norweskich i polskich respondentów dotyczące podejmowania sztucznego odżywiania w zaawansowanej demencji oraz jego efektywności dla tej populacji chorych były znacząco różne. 2. Według większości respondentów prawo do podejmowania każdej decyzji dotyczącej rozpoczęcia sztucznego odżywiania ma jedynie lekarz. 3. Należy opracować ogólne wytyczne i standardy polityki żywieniowej w stosunku do chorych z zaawansowaną demencją, a także wyjaśnić częste nieporozumienia związane z domniemaną efektywnością sztucznego odżywiania w tej populacji pacjentów.
Słowa kluczowe: demencja, dylematy etyczne, sztuczne odżywianie, świadectwo woli.

Background

Older people, often suffering from dementia, are a growing segment of our society. The incidence and prevalence of dementia increases in the population worldwide. Nowadays, it is approximately about 10 million people in Europe suffering from dementia diseases (respectively – about 250 thousand in Poland and 60 thousand in Norway) [1–3, 4]. Moreover, it is estimated that by 2050 this number will be probably doubled, reaching 400 thousand in Poland and 94 thousand in Norway [2, 3].

Dementia is defined as an acquired global impairment of intellect, memory and personality without impairment of

consciousness. The most common causes of dementia are untreatable and the deterioration seen in this disease results in a median survival of about 8–10 years [5].

Nutritional issues in advanced dementia which result in weight loss and malnutrition include apraxia of eating that makes use of utensils difficult, chewing difficulties and food refusal. In the severe and terminal stages of the disease, patients also develop swallowing difficulties and may be unable or unwilling to open their mouths and may tend to turn their heads away or spit out food [6–8]. The most studies on this issue suggest that staff caring for individuals suffering from advanced dementia face different feeding difficulties on a daily basis. The daily dilemma in the dementia care is whether one should initiate therapy, often seems to be futile, or focus on the patient's comfort and let the process of disease take its natural course [6]. Being able to prolong life in some cases may be in conflict with the ethos of caring, which has at its core, empathy for others and the relief of suffering. According to the ESPEN guidelines published in 2005, end-stage dementia is the most controversial issue with regard to artificial nutrition [9]. A severely demented patient is unable to take part in the decision-making process, thus raising many ethical and legal issues associated with artificial nutrition which must be considered. Despite the fact that majority of geriatricians and secular ethicists have argued that artificial nutrition and hydration are indeed forms of medical therapy that can legitimately be withheld if their risks outweigh their benefits, a lot of family members and caring staff repeatedly state that they cannot let patients "starve to death" [7, 10].

Objectives

The aim of the study was to offer an analysis of convictions of Norwegian and Polish caring staff according feeding problems in patients with advanced dementia and explore the way they cope with such situations.

Material and methods

The study involved staff taking care of elderly demented patients in the nursing home "Engensenteret" in Bergen (Norway) and in the Medical Centre nursing home in Brzeg (Poland). All participants were involved in daily care or feeding of patients with dementia. They were enrolled in the study if they expressed consent to participate. The study group comprised 52 participants. The vast majority of the study group were women (88.5%). The age of Norwegian participants ranged from 21 to 63 years (39.6 ± 12.7) and Polish ones from 27 to 54 years (40.9 ± 7.6) ($p = 0.014$). Majority of respondents (73.1%) were Christians. Characteristics of respondents by job position are presented in Table 1.

The data was collected between July and October 2008. The chosen diagnostic instrument was a self-constructed questionnaire. Its first section contained questions about respondents' demographics and job position whereas in the second one, respondents were asked to respond to both open- and close-ended questions regarding their experiences with feeding difficulties of elderly patients suffering from dementia, attitudes towards initiating, withholding or withdrawing artificial nutrition from these patients and beliefs about it.

All data was analyzed and verified statistically using Statistica software (version 10.0). The Fisher exact test (two-sided) was performed for the comparison of categorical variables and the Student's t-test for quantitative variables. The strength of dependence between variables was measured using τ-Kendall's rank correlation test. P-values below 0.05 were considered significant. The normality of data was assessed by Shapiro-Wilk test and it was confirmed that the data followed a normal distribution.

Results

The feeding difficulties reported by respondents are provided in Table 2. The Norwegian respondents claimed to face significantly more "apraxia of eating" in demented patients than Polish ones did $\chi^2 = 6.60$ ($p = 0.01$). The other statistically significant difference is related to "decreased appetite". Polish respondents faced this feeding difficulty in their practice while Norwegian ones did not $\chi^2 = 6.45$ ($p = 0.02$). The Norwegian and Polish respondents differed in ranking the feeding difficulties (τ-Kendall = 0.28; $p > 0.05$). Both groups ranked highest swallowing difficulties (rank 1). Furthermore, difficulties focused upon more heavily by the Norwegian respondents were "apraxia of eating" (rank 2) and "hyperactivity" (rank 3) while Polish respondents gave greater emphasis on the "decreased appetite" (rank 2) and "patients turn their heads away" (rank 3).

Majority of Norwegian respondents answering the question about forced feeding of severely demented patients (89.2%) said they would not initiate it. They indicated such values as an autonomy and respect for patient's rights underlying their decisions. They emphasized also that dementia is a terminal condition and one should let it take its natural course. Four Norwegian respondents (14.3%) gave no explanation for their decisions and three (10.8%) – gave no answer at all.

Contrary to the Norwegian respondents, none in the Polish group (100%) would forgo forced feeding. Although a majority of Polish respondents (54.1%) actually answered negatively to the question about feeding forced by themselves, they would choose to move the severely demented patients to the hospital for initiate tube feeding, which in fact is forced feeding. Others (45.9%) made it clear they would force food on demented patients with different ways. The totally predominant items among Polish staff were the determination to prevent patients from starving themselves to

Table 1. Characteristics of respondents by job position

Job position	Total (*N* = 52) *n* (%)	Norwegian (*N* = 28) *n* (%)	Polish (*N* = 24) *n* (%)
Professional healthcare staff	**41 (100)**	**21 (100)**	**20 (100)**
Nurses	19 (46.3)	8 (38.1)	11 (55.0)
Certified nurses' assistants	10 (24.4)	10 (47.6)	–*
Health care assistants	8 (19.6)	1 (4.8)	7 (35.0)
Nursing students	2 (4.9)	2 (9.5)	–
Dietetician	1 (2.4)	–	1 (5.0)
Physiotherapist	1 (2.4)	–	1 (5.0)
Unprofessional healthcare staff			
Students	**11 (100)**	**7 (100)**	**4 (100)**
Assistants	3 (27.3)	3 (42.9)	–
	8 (72.7)	4 (57.1)	4 (100)

* There is no certified nurse's assistant profession in the Polish Health Care System.
N = number of respondents.

Table 2. The feeding difficulties reported by respondents (each respondent may indicate more than one feeding difficulty)

Feeding difficulties	Total (*N* = 52)		Norwegian (*N* = 28)		Polish (*N* = 24)		*p*-value
	n (%)	*R*	*n* (%)	*R*	*n* (%)	*R*	
Swallowing difficulties	27 (51.9)	1	16 (57.1)	1	11 (45.8)	1	0.58
Apraxia of eating	13 (25.0)	2	11 (39.3)	2	2 (8.3)	4	0.01
Patients turn their heads away	6 (11.5)	3	3 (10.7)	4	3 (12.5)	3	1.00
Decreased appetite	5 (9.6)	4	0	9	5 (20.8)	2	0.02
Hyperactivity	4 (7.7)	5	4 (14.3)	3	0	7.5	0.11
Patients forget to eat	3 (5.8)	6	2 (7.1)	5.5	1 (4.2)	5	1.00
Agnosia	2 (3.8)	7	2 (7.1)	5.5	0	7.5	0.49
Patients spit out food	1 (1.9)	8.5	1 (3.6)	7.5	0	7.5	1.00
Abnormal coordination of movements	1 (1.9)	8.5	1 (3.6)	7.5	0	7.5	1.00
			τ-Kendall = 0.28, *p*-value > 0.05				

N = total number of respondents, *n* = number of answers, *R* = rank of feeding difficulties.

Table 3. Respondents beliefs about the benefits of artificial nutrition in advanced dementia (each respondent might indicate more than one option)

Respondents' beliefs	Positive answers						
	Total (*N* = 52)		Norwegian (*N* = 28)		Polish (*N* = 24)		*p*-value
	n (%)	*R*	*n* (%)	*R*	*n* (%)	*R*	
Improve nutritional status	23 (44.23)	1	9 (32.1)	2	14 (58.3)	2	0.09
Prevent aspiration pneumonia	15 (28.85)	2	5 (17.8)	5	10 (41.6)	3	0.07
Improve pressure ulcer healing	19 (36.53)	3	13 (46.4)	1	6 (25.0)	5	0.15
Decrease hunger and thirst	15 (28.85)	4	7 (25.0)	4	8 (33.3)	4	0.55
Improve quality of life	17 (32.69)	5	1 (3.6)	6	16 (66.6)	1	< 0.001
None of the above beliefs are correct	11 (21.15)	6	8 (28.6)	3	3 (12.5)	6	0.19
			τ-Kendall = 0.47, *p*-value > 0.05				

N = total number of respondents, *n* = number of positive answers, *R* = rank of beliefs.

death and the necessity to preserve a patient's life. One respondent didn't find patients with advanced dementia as individuals who could make a competent decision about their food intake as well. Seven Polish respondents (29.2%) gave no explanation of their decisions.

The most common factors that would change the Norwegian respondents' minds about non-feeding were patient's previously stated living will (60.6%), medical head's order (57.1%) and an underlying acute disease as a reason for food refusal (46.4%). The majority of Polish respondents would be willing to change their mind about forced feeding when it causes suffering in the patient (79.2%) or when the medical head gave them such an order (37.5%). Noticeable is that both Norwegian and Polish respondents did not pay too much attention to requests from patient's family (21.4% *vs* 16.7%).

Almost half of the respondents (48.1%) suggested that any decisions about aggressive nutrition and hydration should be made separately by a physician. Nevertheless, 60% of Norwegian and 25% Polish participants believed that only decision made by interdisciplinary team is ethically correct. This difference between Norwegian and Polish was statistically significant $\chi^2 = 5.47$ ($p = 0.03$). The patients with advanced dementia were not found by any of participant as persons who could make such decisions by themselves. It is noteworthy that none of participants would offer decision-making power to the patient's family or surrogate decision-maker. None of our respondents would take responsibility either to make the decision about artificial nutrition for an incompetent demented patient.

The respondent's beliefs about artificial nutrition are listed in Table 3. The majority of respondents, both Norwegian (71.4%) and Polish (87.5%) believed that initiating artificial nutrition would improve a patient's nutritional status and the healing of pressure sores, prevent aspiration pneumonia in demented patients or improve their quality of life.

The nations differentiated ranking of beliefs is proved by τ-Kendall's correlation-rank coefficient equal to 0.47 ($p > 0.05$). In the rank list of Polish respondents beliefs, "improve quality of life" was at a higher place (rank 1) than the Norwegian ones who placed it far down on the list (rank 6); rendering a statistically significant difference $\chi^2 = 23.38$ ($p < 0.001$). Contrary to Norwegian respondents who ranked belief "improve pressure ulcer healing" highest (rank 1), Polish ones did not pay not too much attention to this belief (rank 5).

Discussion

Recent studies on the study issue, have raised important questions about the ways in which the autonomy of the demented patient can be maintained. Since the patient is incompetent, the use of advance directives would be a preferred mechanism and it should, in most cases, reflect the patient's wishes, moral and religious attitudes [11]. Our study highlighted that the presence of a written living will can alter the respondent's decision in regard to artificial nutrition and hydration. Unfortunately, in many cases advance directives are not available [5, 12]. Even in the United States, where already since 1991 federal law has required that every hospitalized or institutionalized patient be informed of his/her right to use medical advance directives, there is only a small group of patients who have completed their living will [11]. The one form of advance directive available in Norway (the Life Testament) is neither legally binding nor commonly used by Norwegians [13]. In Poland, the establishment of a living will is neither legally nor common practice.

When a patient's preferences are unknown, a detailed discussion within the multidisciplinary team is necessary. There are physicians who make final decisions but they should discuss it with the family and all members of the multidisciplinary team [14]. Unfortunately, this view was supported only by a part of respondents in our study. Almost half of them would delegate responsibility separately to the physician. They did neither offer the decision-making power to the patient's fam-

ily. Although the best practice dictates that where patients lack capacity, decisions should involve discussion and consultation with the family, it is rarely done. Family members often feel that things are "out of their control" and they cannot influence decisions directly affecting their relatives [14].

The caregivers have no decision-making power in determining whether a patient could be selected or declined for artificial nutrition but these caregivers who have a strong understanding of disease process could influence a physician's recommendation of tube feeding and educate families regarding the justification for such interventions. However, the recent literature gives the impression that both physicians and family members are not well prepared for their decision-making roles. A cross-national study of substitute decision-makers found that the majority of them felt they understood the benefits (83%), but not the risks (48.9%) of tube feeding [15]. Another study suggested that primary care physicians recommended PEG tube placement because they overestimated the efficacy of this intervention [16].

By initiating any type of artificial nutrition, decision makers expect that it would improve patient's nutritional status and the healing of pressure sores, prevent aspiration pneumonia in demented patients or improve their quality of life, which is certainly not supported by literature [12, 17–19]. The majority of our respondents, both Norwegian and Polish held on to these beliefs as well.

Among the most notable observations in our study was a significant difference between Norwegian and Polish respondent's attitudes toward artificial nutrition in end-stage dementia. Contrary to the Norwegians, all Polish respondents favored it. One of possible explanations for this observation is the paternalistic approach to patients, which still exists in Polish healthcare system [8]. Polish respondents stressed sanctity of life as a dominant value whereas for their Norwegian counterparts extending of life was not as important as assuming quality, dignity and comfort. There are no similar studies in Poland but these attitudes seem to be in line with some results of international studies published by other researchers. In particular Norberg et al. [20] found that there are clear differences between nurses' attitudes toward artificial nutrition and hydration in different countries. Whereas western informants (Australian, Canadian and Swedish nurses) were more likely to choose not to feed and more likely to cite autonomy in this connection, informants from other parts of world (all Chinese respondents and 90% of the Israeli nurses) were more inclined to argue for feeding such patient and gave a high rank to the principle of sanctity of life.

Conclusions

1. There was a significant difference between Norwegian and Polish respondents' convictions according introduction of artificial nutrition in end-stage dementia.
2. Almost half of respondents would delegate the decision-making power separately to the physician.
3. The majority of respondents believed that initiating artificial nutrition would improve the various aspects of patients health.
4. The development of nutritional guidelines for advanced dementia and correction of common misconceptions about the effectiveness of aggressive nutritional intervention in this population is recommended.
5. However, in the care of elderly people in end-stage dementia no generalizations should be made because every patient is unique. Artificial nutrition and hydration is not futile in all cases.

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